ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 211. Autumn 2020

This September share your story and set yourself a challenge!

Ataxia people • Research
• Ataxia awareness • Health & wellbeing • Fundraising
Adaptations • Living with ataxia • Services

ATAXIA
Ataxia UK

In the office

Jess Lewis

We are sorry to say goodbye to Jess Lewis, our **Communications Intern**, who has provided a fantastic contribution to the Ataxia Magazine and social media, while replying to many and getting to know the ataxia community. Best of luck to Jess who will start her final year of university.

Welcome

Dear Friends,

I hope that you are managing to stay safe and well.

Although the lockdown is loosening, we don't yet feel that we should reopen the office; so we are still working remotely. Much can progress normally, but other things, such as fundraising events (p.10, 14), our **InControl volunteering project** and our **Annual Conference**, will be immeasurably different for some time to come. We hope, despite the many changes provoked by the epidemic, you will be able to continue to give your support to enable the work of the charity to continue unhindered, and join in with our various activities including **International Ataxia Awareness Day** (p.10) and the **Virtual Annual Conference** (p.20).

The impact of Covid-19 on the NHS, employment, and many aspects of everyday life, has been huge. Most of the expert ataxia neurologists have continued to provide appointments by telephone or video; and we are keen to understand your experiences of this. But in general, NHS neurology services across the UK have suffered badly, and you may have had cancellations or delays to appointments. Along with other neurological and rare disease charities we are pressing hard for their re-instatement, and improvement, as even before Covid-19 there were many shortcomings for people with ataxia in general neurology. If you have a story to tell about your neurological care, good or bad, please let me know.

Best wishes,

Sue Millman

KEY CONTACTS

- **Sue Millman**
- Chief Executive
smillman@ataxia.org.uk

Services

- **James Atkins**
- InControl Community Programme Manager
volunteering@ataxia.org.uk
- **Sheila Benneyworth**
- Helpline and Membership Officer
helpline@ataxia.org.uk
0800 995 6037

Research

- **Dr Julie Greenfield**
- Head of Research
research@ataxia.org.uk

Fundraising & Communications

- **Dan Beacon**
- Head of Fundraising and Communications
- **Kelvin Gichohi**
- Individual Giving Manager
- **Rebecca Holt**
- Community Fundraising Manager
fundraising@ataxia.org.uk
- **Leanna Coleman**
- Communications Officer
communications@ataxia.org.uk

For queries or feedback please contact Leanna Coleman.

Contact our office

office@ataxia.org.uk

020 7582 1444

Ataxia UK, 12 Broadbent Close
London N6 5JW

www.ataxia.org.uk

Ataxia people

- Lockdown isn't so bad after all …
- Network updates — 4

Research

- FA project: new treatment options
- ESMI results — 6

Ataxia awareness

- IAAD: Raising awareness
- 10.5 for 10.5 challenge — 10

Health & wellbeing

- Ataxia and exercise - what does this mean for you? — 11

Fundraising

- The Big Give Challenge
- FootyFivers • Fundraising highlights — 12

Adaptations

- Introducing … James Downie
- Making your home the right fit — 16

Living with ataxia

- Adjusting to lockdown — 18

Services

- Ataxia UK's Virtual Conference
- Harriet's take on our virtual activities — 20

Lockdown isn't so bad after all…

Kizzy last wrote in issue 208 about Mum, Kathy, and her trips out. Here they share their thoughts and adventures during lockdown.

I was made redundant before the start of lockdown. The TV was filled with news of mass panic buying, the virus spreading and discussions of imminent lockdown. I soon realised perhaps my redundancy would be a blessing in disguise during the following months.

Mum was becoming worried about the situation, so we decided that the first step to improve her mood was a farewell to the TV. Mum normally uses the TV as company, so this was a big step for her, and we switched to Virgin Radio as this was the most positive. We planned our menus more, including lots of extra vegetables. A family friend was kind enough to do our shopping while she was out, so I didn't need to worry about the supermarket.

We have spent lots of time in the garden working on projects; we've painted the shed bright colours, built fun areas in spaces that were previously drab and dingy, and Mum has chosen some vegetables that are thriving. We have raised beds so they are easily accessible for Mum to sit and work at; the roses have been especially joyful this year. I ensure that Mum spends plenty of time outside enjoying the wonderful garden we have created and often we will have lunch together outside or play Scrabble.

We are staying social; Mum has phone calls with family and video calls provide a real boost to her wellbeing. We really enjoy sitting in our front garden and chatting to our neighbours.

Being at home full time has given me the opportunity to learn more about how ataxia affects mum daily. I am constantly trying to work out new ways to make her life less challenging. I also encourage her to open up about struggles, rather than bottle it up or ignore it.

While we have our fun projects on the go, I try to ensure Mum doesn't overdo things. I remind her we are in no hurry and have plenty of time (finally we have more time than three months of Sundays!). This has made everything more enjoyable for both of us. Plans have been cancelled and our normal routine has completely gone, but for now we are happy, content and safe, and plan to stay that way.

Support Group spotlight

Ataxia UK has over 50 Branches and Support Groups run by volunteers across the country. They are imperative in providing support to thousands of people affected by ataxia. Due to Covid-19, face-to-face meetings have come to a halt, however, co-ordinators are making a brilliant effort to provide support and include all members. Some groups are meeting virtually, while others are producing and sharing newsletters. If you would like to join a Support Group, you can find one closest to you by visiting:
www.ataxia.org.uk/Pages/FAQs/Category/branches-and-support-groups

Governing Ataxia UK: changes to the Board of Trustees and Ataxia UK constitution

In the last magazine we reported that there will be no Trustee Elections this year. This is due to the Ataxia UK's Board of Trustees reviewing how it operates: in particular, the skills and diversity of Trustees; the number of Trustees; the way Trustees are recruited; ways of developing potential Trustees from among Friends, and Trustee's length of service on the Board.

This has produced a number of proposed changes to our constitution which would:

- **Reduce the size of the Board from 14 to 7-10 members** - elected Trustees would remain in the majority and the opportunity for three people to be appointed as Trustees by the Board, rather than elected by Friends, will remain.
- **Introduce interviews for potential Trustees** before standing for election or being proposed to the Board.
- **Establish a number of sub-groups and formal sub-committees** covering all aspects of Ataxia UK's work in detail.
- **Foster a pipeline of potential Trustees by recruiting Friends** to serve on sub-groups/committees to gain experience before putting themselves forward for a Trustee position. This will enable more Friends to be engaged in the governance of the charity.
- **Develop training for Friends volunteering on sub-committees/groups** through the InControl volunteering project.
- **Restrict the term of a Trustee to six years** (two consecutive periods of three years, then a retirement for a minimum of a year would be required before re-standing).

*These potential changes will be discussed and consulted on in detail during the **Ataxia UK Virtual Conference** (see p.20).*

Since lockdown our helpline number has changed to

0800 995 6037

*and it is **FREE** too!*

Please note down the number and share with the ataxia community.

FA project hopes to identify new treatment options

Ataxia UK is pleased to have awarded a grant to Dr Benoit D'Autréaux, at the University of Paris-Saclay, to support his Friedreich's ataxia (FA) research.

Dr D'Autréaux and his team (right) have proposed a new strategy to find potential treatments for FA, thanks to an experiment that uncovers how frataxin carries out its enzyme function.

Genes contain instructions to make protein. FA is caused by a genetic mutation in the frataxin gene. This mutation causes less frataxin protein to be produced. Therefore, people with FA have roughly 5-10% of the frataxin protein that would be found in the cells of someone without FA.

Frataxin has an important role in some cellular functions, but because people with FA have less frataxin, these functions are not carried out effectively. One function is as an enzyme in specific chemical reactions, which occur inside cells (enzymes make chemical reactions faster and more efficient). Losing this enzyme function of frataxin starts a chain of events, which eventually leads to the symptoms seen in FA.

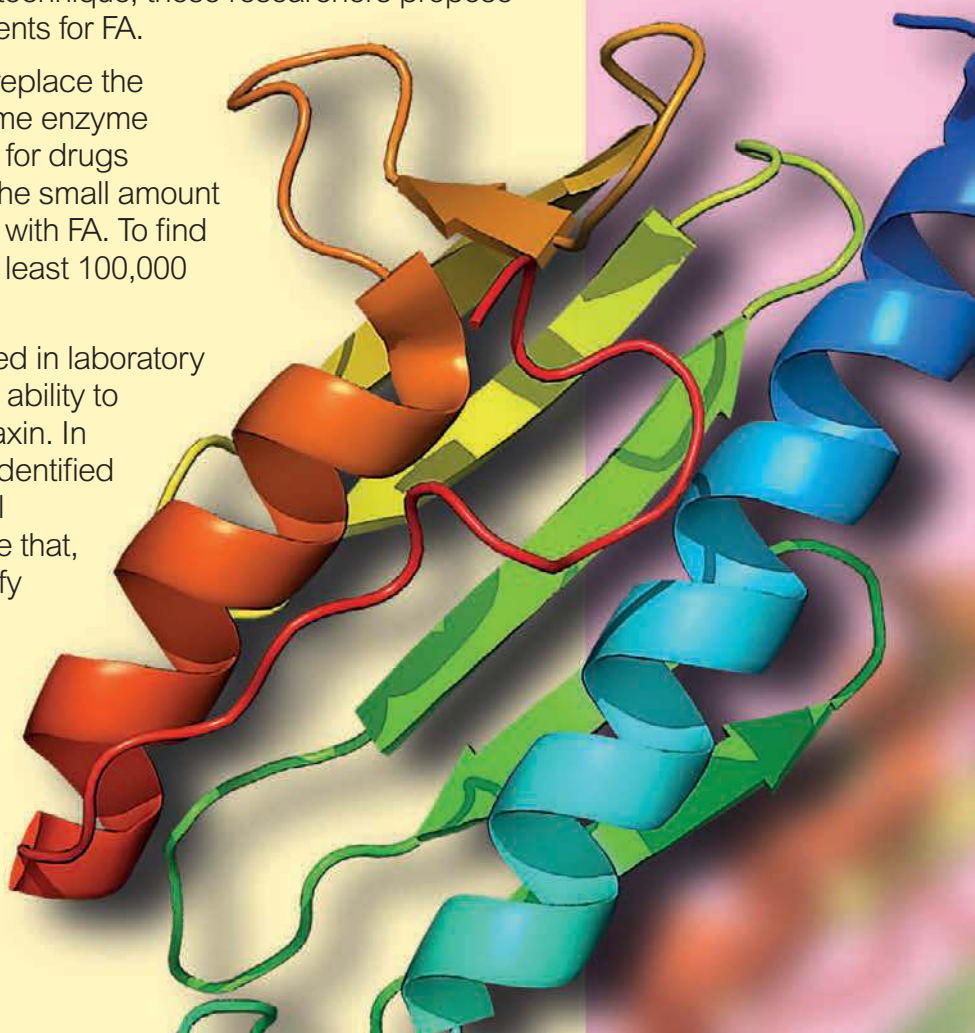
Until recently, it was very difficult to measure how efficiently frataxin was carrying out its enzyme function. An experiment developed by Dr D'Autréaux and his team recently made this possible, so they can now measure the enzyme activity of frataxin. Using this technique, these researchers propose a new strategy to find potential treatments for FA.

They aim to identify drugs that would replace the frataxin protein by carrying out the same enzyme function as frataxin. They will also look for drugs that enhance the enzyme function of the small amount of frataxin found in the cells of people with FA. To find these drugs, they initially aim to test at least 100,000 different chemical compounds.

To begin with, these drugs will be tested in laboratory experiments that simply measure their ability to replace or enhance the activity of frataxin. In future work, any compounds that are identified will be further tested in cell and animal models of FA. These researchers hope that, eventually, any compounds they identify could be tested as treatments for FA.

Dr D'Autréaux said: "We are pleased to have received funding to be able to continue with this important work. We are hopeful that our innovative technique could identify new treatment options for people with FA."

Below:
Image representing the frataxin protein.



Diagnosing and treating primary autoimmune cerebellar ataxia (PACA)

Many people with ataxia are not given a specific diagnosis for the cause of their ataxia. This is known as idiopathic ataxia.

In two new publications, **Professor Hadjivassiliou** (below) at the **Sheffield Ataxia Centre**, and his colleagues, describe a type of ataxia that could be responsible for a number of idiopathic ataxia cases. They explain how neurologists can make this diagnosis and how this type of ataxia can be treated.

Immune-mediated cerebellar ataxias are caused when the body launches an unnecessary immune reaction against the cerebellum (the balance centre) causing damage, resulting in ataxia. Gluten ataxia is an example of an immune-mediated cerebellar ataxia. In patients with gluten sensitivity, the body recognises gluten as harmful and produces antibodies against it. These antibodies travel to the brain and attack cells of the cerebellum, which results in ataxia. In this case, gluten is known as the 'trigger'. However, in some cases of immune-mediated ataxias, the trigger is unknown, which is when the condition is called primary autoimmune cerebellar ataxia (or PACA).

DIAGNOSING PACA

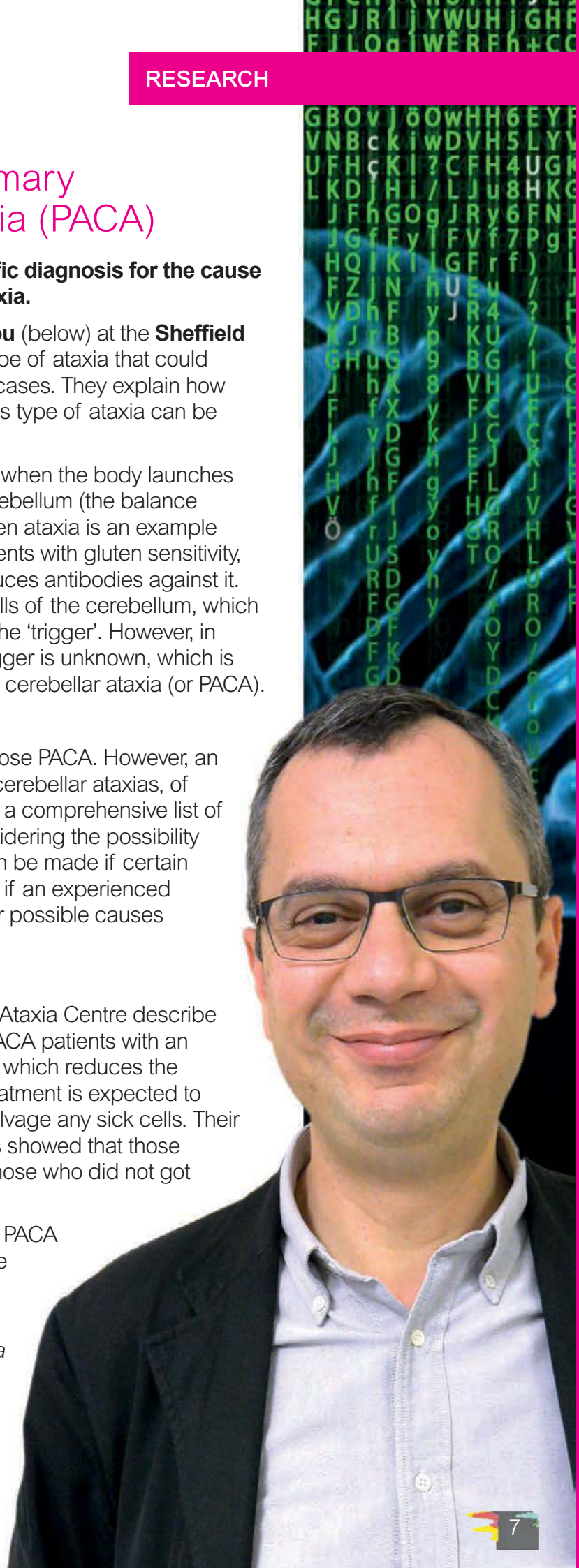
There is no specific test that will definitively diagnose PACA. However, an **International Task Force** on immune-mediated cerebellar ataxias, of which Prof Hadjivassiliou is the lead, have written a comprehensive list of clues that neurologists should look for when considering the possibility that a patient has PACA. A diagnosis of PACA can be made if certain criteria outlined in this document are fulfilled, and if an experienced neurologist or ataxia specialist has ruled out other possible causes (such as genetic ataxia).

A TREATABLE FORM OF ATAXIA

In the second article, the team from the Sheffield Ataxia Centre describe a possible treatment for PACA. They treated 22 PACA patients with an immunosuppressive drug called Mycophenolate, which reduces the immune response that causes the ataxia. This treatment is expected to prevent further damage to the cerebellum and salvage any sick cells. Their results using brain scans and ataxia rating scales showed that those receiving treatment improved or stabilised, and those who did not got progressively worse.

Prof Hadjivassiliou said: "Identifying patients with PACA is incredibly important to allow them to receive the appropriate treatment, and early diagnosis could prevent permanent neurological damage."

If you have been diagnosed with idiopathic ataxia and would like to explore the possibility of PACA, we recommend you speak to your neurologist about these new publications. If you do not see a neurologist regularly, email ***help@ataxia.org.uk*** *for details of* ***Specialist Ataxia Centres****.*



European Spinocerebellar Ataxia Type 3/ Machado-Joseph Disease Initiative (ESMI) results

BACKGROUND

To design and run successful trials it's important to understand SCA3 and its progression, and develop the best way to measure the potential effect of a medication in a trial. A few years ago six European Centres with expertise in ataxia created a European Consortium to study SCA3. The Consortium obtained funding from the EU Joint Programme on Neurodegenerative Disease Research (JPND) for a collaborative project called ESMI. This four-year study has recently completed. ESMI involved Centres in Bonn, Azores, Coimbra, Tübingen, Nijmegen and London, plus associated partners in Aachen, Essen, Heidelberg, Groninberg and Santander. Euro-ataxia is a collaborator and Ataxia UK's Head of Research, Julie Greenfield, has been the Euro-ataxia representative on the Steering Committee. We are very grateful to all Friends who travelled to the London Ataxia Centre and participated in this important study.

RESULTS

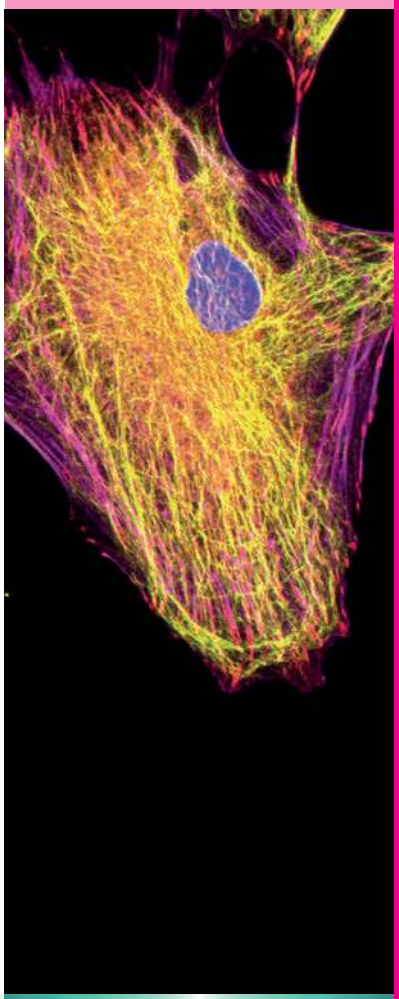
The ESMI Consortium has successfully characterised the largest cohort of patients with SCA3 worldwide, consisting of around 270 SCA3 mutation carriers (majority with SCA3 and a small proportion of pre-symptomatic individuals) and nearly 100 age-matched healthy control subjects. This is an extremely useful resource for running trials in Europe. The Consortium established a protocol for measuring volumes of particular regions of the brain using MRI. It was already known that the brain in SCA3 has less volume of particular areas, but ESMI helped discover that a certain brain region starts decreasing up to 20 years before ataxia onset, meaning it's a very sensitive measure of the condition, and useful in clinical practice and trials. Researchers also identified a 'marker' that could be measured in blood samples, and which indicated the presence of nerve damage. This could also be useful in future trials.

SCA3 is caused by the accumulation of mutated ataxin 3 protein (toxic to cells). Future gene therapy trials will attempt to silence the gene and reduce the amount of mutated ataxin 3 protein. To measure its success, it's essential to measure the reduction in the ataxin 3 protein. This Consortium developed an ultra-sensitive test using body fluids that provides a significant step for future gene therapy trials in SCA3. Lastly, ESMI completed the first assessment of the impact of lifestyle on SCA3 worldwide.

FUTURE PLANS

The ESMI Consortium has laid important foundations for future clinical trials. This is reflected by huge interest of academic institutions and industry companies in long-term cooperation with ESMI to ensure the project can continue. *For more information see* ***issue 203*** *and* ***www.euroataxia.org***.

An ARSACS project, funded by Ataxia UK and the ARSACS Foundation in Canada, has finished with positive results.



Autosomal recessive spastic ataxia of Charlevoix-Saguenay (ARSACS) is a rare inherited ataxia caused by mutations in the **SACS** gene, which leads to a loss of function of a protein called sacsin. As with other ataxias, over time, sacsin-deficient neurons in the coordination centre of the brain (cerebellum) degenerate and die. It is not clear why loss of sacsin causes this to happen, but understanding this process is a crucial first step towards identifying potential treatments for ARSACS.

Cells, including neurons in the brain, contain an interconnected network of protein threads known as the cytoskeleton (see pink and yellow in image on right). This plays an essential role in maintaining cell shape and internal organisation, as well as facilitating cellular movement. **Professor Paul Chapple** and his team at Queen Mary University of London set out to understand whether problems with the cytoskeleton had a role in the cellular pathology of ARSACS. They showed widespread disruption of the cytoskeleton in cells where they had experimentally deleted sacsin. In addition to disruption of the cytoskeleton they discovered that cell movement and migration was impaired in the absence of sacsin. This is important for ARSACS research because preventing or repairing this cytoskeleton damage, with drugs or other mechanisms, could be a future treatment for this ataxia.

Friedreich's Ataxia Global Patient Registry (FAGPR)

The FAGPR, launched in November 2019, is your link to the world of FA research. This registry will help researchers learn more about FA directly from patients, and will also be used to recruit people to take part in clinical trials and research projects. Ataxia UK's Research team held a webinar[o] in June to explain the aim of the registry and how to join.

You can view a recording on our website ***www.ataxia.org.uk/news/for-people-with-friedreichs-ataxia****. Email* ***research@ataxia.org.uk*** *for more information.*

SCA and ARCA Global Conference

SCA and ARCA Global are worldwide projects aimed at harmonising the way clinicians collect data from patients with dominantly and recessively inherited ataxias, respectively. The aim of these projects is to ensure the ataxia field is ready for clinical trials when possible treatments become available. Dr Julie Greenfield, Head of Research, is on the steering committee for both of these initiatives. We are pleased that the SCA and ARCA Global Conferences, cancelled earlier this year due to the Covid-19 pandemic, will now be held remotely on **19-21 October 2020**. We will include research updates from the conference in future magazines.

ARCA GLOBAL

SCA Global

IAAD: Raising awareness of difficult diagnosis

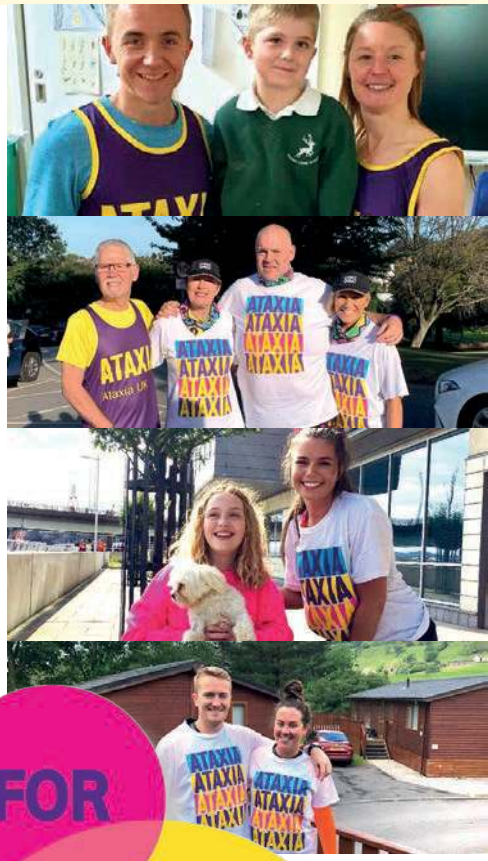
An estimated 10,500 people have ataxia in the UK, but gaining a diagnosis is challenging. This International Ataxia Awareness Day, help highlight this problem and transform diagnosis for others.

For many with ataxia it takes years to get a diagnosis, and the journey itself is distressing. We have heard stories of wrong referrals; people being turned away and feeling as though there is nowhere else to turn. Did you have a difficult diagnosis, or are you currently going through one? This September we need you to share your ataxia diagnosis with the world. Together, we will highlight this issue and raise awareness of ataxia across social media.

HOW TO TAKE PART ON SOCIAL MEDIA

- **Share your story:** whether you have a full diagnosis or still waiting for results, email your story to **communications@ataxia.org.uk** and we will share
- **Follow and like our social media platforms; share our posts:** **@ataxiauk**, **@AtaxiaUK**, **@ataxia_uk**
- **Sign up to our E-newsletter:** receive campaign materials for the day
- **Use the hashtags: #TenPointFive #AtaxiaUK #IAAD**

Take part in IAAD with the 10.5 for 10.5 challenge



As Covid-19 continues to impact lives, it is hitting communities, particularly ours, even harder. We are doing everything we can to continue providing support. You can help ensure this happens by taking part in the 10.5 for 10.5.

WHY 10.5?

10.5 represents the 10,500 people in the UK with ataxia. By doing 10.5 for 10.5 between **1 September and 31 October** you will be the hope to transform lives with ataxia; raising funds and awareness.

HOW DO I TAKE PART?

Challenge yourself to do 10.5 of anything you like! Run, walk, cycle, wheel, sing or anything in-between! Take part individually or with friends, just make it 10.5 or 10,500.

SOME IDEAS TO GET YOU STARTED:

- 10.5km run, walk, wheel or row
- 10,500 steps a day for a week or join with friends to hit the total together
- Skip 10,500 times.

Find out more and register at:
www.ataxia.org.uk/tenpointfive
Email: ***fundraising@ataxia.org.uk***

Welcome to the team, and thank you for being part of the 10.5 for 10.5!

Ataxia and exercise - what does this mean for you?

Heather Mantle is a physiotherapist who works with neurology patients. Heather tells us what is important to consider when exercising.

When thinking about ataxia and how it relates to exercise, for example, it is tiring, hard work, painful and difficult to do, you may feel that it's not for you. The worries over exercise and initiating it are, understandably, exacerbated in the current climate where many people are confined to their homes and stress levels generally are higher, thus making it more difficult to get motivated. However, wherever there is a bed, chair or floor available to get up from, exercise is possible.

There is no set of exercises that will suit everybody. It's important to try a range of exercise, whilst remaining safe, of course! The body needs to be tested at times and you may surprise yourself in what you can achieve, particularly if it is something new and beyond what you believed to be your own capabilities.

When considering to attempt exercises, follow these golden rules:

- **Check with your doctor or physiotherapist which exercises are best for you, everyone is different**
- **Fatigue is one of the biggest problems to overcome, it is important to pace yourself**
- **Try to keep an open mind when trying something different**
- **Find something enjoyable to do as you will be more inclined to stick with it**
- **Remember at all times that the focus is on you**
- **If standing, be sure that this is attempted in a controlled environment where there is something static to hold on to**
- **It is important not to push yourself or attempt more than you feel comfortable with; every day is different**
- **Try to focus on your core, hip strength, legs and upper limbs; if these are strong it may encourage your limbs to move more easily**
- **Try to exercise little and often; don't attempt too much!**

It's important to remember that you can do it! Have faith in yourself and follow the guidelines laid out for you above. Remember to stay safe and seek guidance from your doctor or physiotherapist before trying out new exercises. Thank you to my friend ***Beverley Batt*** *for supporting me in writing this article.*

The Big Give Challenge returns this December!

Save the date: Help fund the Ataxia UK helpline and research

ONE DONATION, TWICE THE IMPACT

It's that time of the year again, folks! Your one-week opportunity to double the value of your donations to Ataxia UK at no extra cost.

Now, more than ever, it's an important time to help protect the future of vital ataxia support services and continue to accelerate research towards finding new treatments and a cure.

YOUR MATCHED DONATIONS WILL BE MORE IMPORTANT THAN EVER

The Covid-19 pandemic has had a devastating impact on the ataxia community. But, at a time when we need to do even more to provide crucial medical guidance and support to the most isolated and vulnerable people living with ataxia across the UK, **we are facing a devastating drop of more than £250,000 in fundraising income as a result of the crisis**. The loss of this income will have a significant impact on our ability to fund vital services to those who need our support the most in the years to come.

That's why this year, for one week only, you can double your donations and help fund our helpline and continue research into the ataxias, at no extra cost!

SAVE THE DATE

From **12pm on 1 December until 12pm on 8 December**, we urgently need your help to raise £80,000 to help fund two core areas of our work:

1. Support ongoing provision of the Ataxia UK helpline in 2021 - expanding on the advice and support we provide, particularly for people affected by ataxia in financial hardship following the pandemic.
2. Continue to commission research into finding treatments and a cure for the ataxias during these tough times.

HOW IT WORKS

If you would like to make a donation to Ataxia UK this December, please remember to save the date and donate between **1 and 8 December 2020** to double your donation.

Say you donate £50 online through our Big Give donation page between **1 and 8 December** and Gift Aid that donation, your gift will be worth an incredible £125.

Please stay tuned for more information on this year's Big Give Challenge. We will reveal more information and the URL to donate in the next issue of the magazine. If you have any queries in the meantime, please contact ***Kelvin Gichohi, our Individual Giving Manager, at fundraising@ataxia.org.uk***

Chance2Win Winners

1st Prize: £500
William Bowdrey

2nd Prize: £250
Mike Thompson

3rd Prize: £150
Name withheld

Leave a gift in your Will

Forward thinking today can help Ataxia UK find effective treatments and a cure through world-class research tomorrow.

Until a cure is found, Ataxia UK is committed to supporting people who are living with ataxia, their family, friends and carers.

Writing a Will is one of the most positive things you can do for your family and loved ones. But once you've provided for those closest to you, including a gift in your Will to Ataxia UK is a wonderful opportunity to help provide support services for the ataxia community and fund vital ataxia research.

The gifts our supporters leave in their Wills are incredibly important for ataxia research and help fund services such as the helpline, information and advice on financial grants and to connect people to the Branches and Support Groups across the UK.

REQUEST YOUR FREE WILL WRITING GUIDE TODAY

Writing or updating your Will may seem daunting, but it's a vital part of planning for the future so that your money and possessions are passed on in the way that YOU want.

This is why we've produced a **FREE Will writing guide, codicil form and Will writing checklist** to help you understand the Will writing process and plan for the future. Our booklet will help you understand why you should consider leaving a gift in your Will to Ataxia UK. It includes practical tools that explain how to leave a gift and information about what kinds of gift you can leave.

If you haven't written a Will before, it will help you get started, let you know what to expect from the process, and provide a checklist of what you'll need.

To request this guide by post, please fill out the enclosed form and return to Ataxia UK using the FREEPOST envelope. We will make sure you receive your legacy guide pack within 7-10 days.

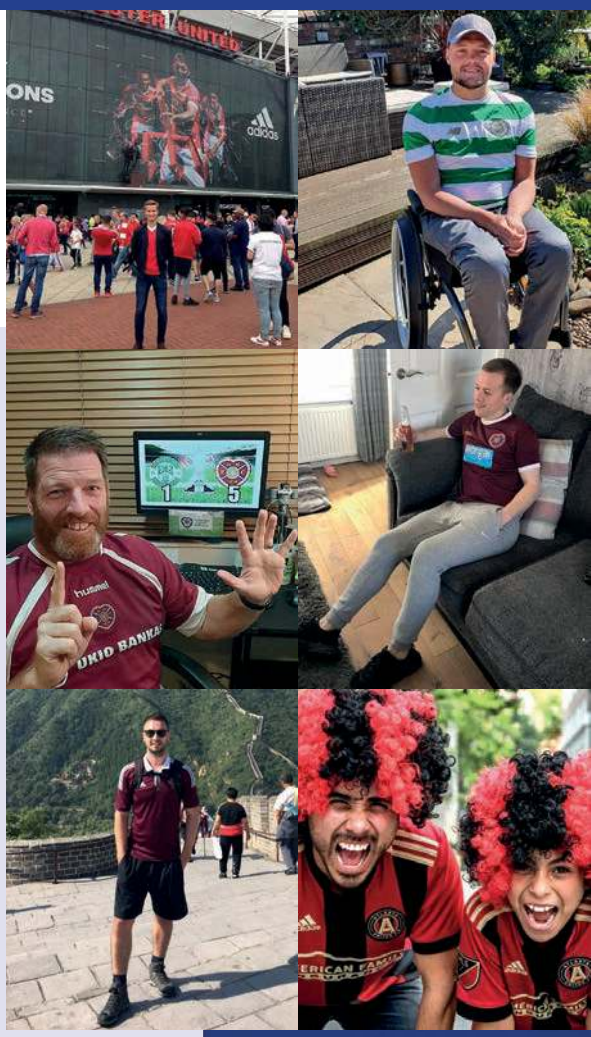
CONFIDENTIALITY

Please note, we will never pressure you to tell us your decision about leaving a gift to Ataxia UK. Anything you do tell us is confidential and is not legally binding. If you would just like to notify us that you intend to leave a gift in your Will, please do let us know your intentions using the enclosed slip - it really means a lot to us and lets us plan for the future with more confidence. Rest assured that your plans will be kept completely confidential.

CALLING ALL FOOTBALL FANS!

As Covid-19 has stopped our usual fundraising streams, we really need your help to ensure fundraising continues. There are lots of ideas on our website, and here is one we'd love you to get involved in!

Until you can get back to the ground to cheer your team on, **#FootyFivers** is the perfect way to support both your team and Ataxia UK!



THREE SIMPLE STEPS TO GET INVOLVED

1 **Share a photo on social media** in your team shirt telling everyone why they are number one, including the following in your post to explain the campaign and why taking part is so important:

As we can't go and see our teams play, I am supporting mine, and Ataxia UK, by sharing a photo in my team shirt, telling everyone why they're number one and donating £5 to Ataxia UK that I would have spent on a pint and a burger, a scarf or half-time coffees. Ataxia UK is a small charity working hard to find treatments for the ataxias; a group of rare, neurological conditions. They can be life-limiting and devastating. Find out more and donate: ***www.ataxia.org.uk/Appeal/footyfivers #FootyFivers #TeamAtaxiaUK***

2 **Donate the £5 to Ataxia UK** that you would have spent on a burger, scarf or coffees at **www.ataxia.org.uk/Appeal/footyfivers**

3 **Tag five friends** asking them to do the same!
Social handles to use: **@ataxiauk** **@AtaxiaUK** **@ataxia_uk**

You are part of a nationwide campaign as the 12th member of your team - cheering on your football club and helping to fund research into treatments whilst supporting those affected. Thank you.

Tagging your mates helps keep the ball rolling and reach even more people! Ball - rolling, get it?! We are talking about football!

This campaign is the inspired idea of top supporter **Connor Beveridge** (top right) who kicked it off and got his mates involved across social media. You can see them above proudly wearing their shirts and raising money and awareness - thanks so much guys.

Now it's your turn! Time to get your kit, tag your friends and donate!

Questions? Catch us on ***fundraising@ataxia.org.uk***

the 2.6 challenge

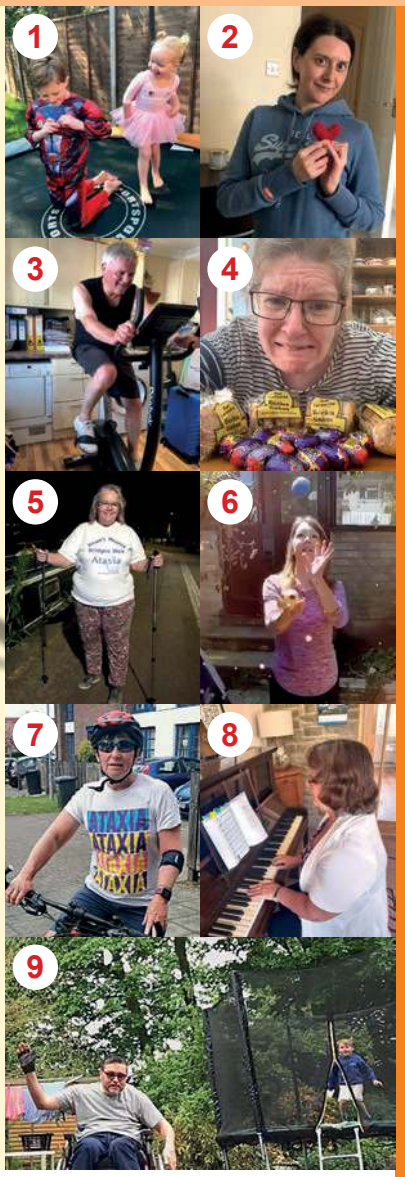
Congratulations 2.6 Challengers! Together you raised a whopping £8,833 plus Gift Aid, we are so grateful for your awesome efforts. Here is what some of #TeamAtaxiaUK got up to …

Congratulations to our youngest challengers **Mollie and Jacob (1)** who jumped on trampolines and beds for 2 minutes 6 seconds, together with their friends **Oscar** and **Ethan**! Another fab young challenger was **Kai Doran** (right) who impressively completed 2.6 miles on his unicycle!

Not letting being at home stop them, **Grace Kay (2)** knitted 26 toys, **Nicki Glazzard** wheeled 26 times around her garden and **Tina Challis** did 26 laps on a tricycle. **Jonathan Mantle (3)** biked 26.2 miles and **Mari Akhurst** bounced a ball 26 times. Really taking the biscuit was **Harriet Bonney (4)** eating 13 Eccles Cakes and 13 Creme Eggs in 2.6 hours!

Getting sporty, **Richard Bradford** cycled 26 miles, climbing 2600ft, **Lucy Smith** ran 2.6km 26 times, and **Carrie Rutherford (5)** walked a marathon in 10 days! Well done to the **Loach family** - **Amy** jumped, **Harry** did press-ups, **Jack** ran and **Yvette (6)** juggled 26 times! And the **Docherty family (7)** who ran 2.6 miles, cycled 26 miles and completed 26 sit-ups!

Our Trustees got involved too; **Kathy Jones (8)** beautifully played the piano for 2.6 hours and **Richard Brown (9)** travelled his garden 26 times. **Andrew Downie** climbed his stairs 26 times, and friend **Beth Watson** mastered 26 challenges in her Chalk Walk!



A huge thank you to everyone who has been doing their own lockdown challenges. Such creative ways to ensure your fundraising continued, and we are so grateful.

Thank you **Andy Grant** (right) for rowing 10k a day for a month, raising a fantastic £1,056! Well done **Dion Ross (10)** who raised a fab £515 by shaving his head! Thank you **Nick Jackson** and **Long Eaton Dawnbreakers Rotary** for kindly donating £500 in place of their Quiz.

Congratulations **Wez Spenceley (11)** for virtually Climbing Everest with an impressive 58,070 steps in 8 hours, raising a smashing £1,739! A big thank you **Lisa, Neil, Matthew and Jack (12)** for virtually walking up landmarks, including the Leaning Tower of Pisa, totalling 748 flights and raising a fab £290!

Congratulations **James Riley (13)** and **Kane Cooke (14)** who pushed their fitness limits and went all out. James completed his own garden marathon and Kane did his first ever half marathon. Both took their motivation from their close relatives with FA, James' son **Thomas**, and Kane's niece **Mollie**. They raised a massive £2,758 and £1,803 respectively. Thank you both so much.

Introducing … James Downie

Each issue James will share insight into his life with ataxia.

Hi everyone,

For those who don't know me, my name is James Downie, for those who do, my name is still James Downie!

It is with great sadness that I take the place of **Matthew Law** with this page. I had met Matthew many times as he supported and attended many of our events over the years. He even treated me to a Chelsea game a few years ago. Maybe treat is the wrong word…

I am 40 (had a lockdown birthday) and was diagnosed with Friedreich's ataxia (FA) in 2001. Since 2006 I have, pretty much, been a full-time wheelchair user. I still drive and I have a Motability car that looks fast, but isn't! I use a manual chair mainly, but I have a power chair and recently got a tri-ride.

I'm a former **Ataxia UK Trustee** and former **South Downs Branch Chairman**. My dad, **Andrew Downie**, is currently a **Trustee for Ataxia UK**.

I live with my wife **Kelly**, our boy **Liam**, and a dog who is definitely not a carer dog! Our son is starting school this September. We live in an adapted bungalow in Byfleet, Surrey, near where I grew up in Woking.

I went to university to study Multimedia in Brighton, where I lived until 2007. I currently work part time at a school in Woking, mainly doing IT support. I have worked many different jobs over the years; I worked in fashion retail and in a bank before I was diagnosed. Since using a chair, I have worked for the council as a youth worker, a web designer (still do this a little bit) and, until recently, a wheelchair skills trainer and club leader for a charity called **Whizz-Kidz**.

I love sport; watching live and on TV. I go to Wimbledon every year (but not this one!), National Football League (NFL) and many football games. I had tickets for the 2020 European Football Championship, but that's been postponed until next year. I go to the odd gig, especially now as the bands and music I loved in the 90's are back. I recently went to see Liam Gallagher (he isn't why our son is called Liam!). I also collect trainers and have too many to count!

If you have any questions or suggested topics you would like me to write about, I would love to hear from you. Email me at ***downstar@mac.com***

Thanks, James

Make your home the right fit

There are different ways to adapt your home so it's safe and comfortable. Keep reading to find out where to get started.

Adapting your home can make everyday tasks easier and, therefore, more enjoyable. There are various changes, some are small, but others are bigger, for example, widening doorways, fitting a stairlift, lowering kitchen worktops, adding an outdoor ramp, or adding a rail or a wet room to your bathroom.

You will need to book a home assessment and this service is free. You can call your local council or book an appointment online. This will be carried out by an **occupational therapist (OT)** who will assess your needs and advise what is best for you. Together you can work out what you need.

It's a good idea to think about the challenges you face each day, despite how small they are, and make a note of them. When the OT carries out the assessment you can tell them everything without needing to think on the spot. You can ask a relative or friend to be with you at the assessment if that makes you feel more comfortable.

Alternatively, you can find an advocate who will speak on behalf of you and help you fill in forms. Visit this page to find out more information on advocates:
https://bit.ly/3fSmTB5

Your local council may pay for some adaptations, so you should check with them what is eligible. For bigger adaptations that are more costly, you may be able to get a grant.

There are many free resources online that offer information about adapting your home. Visit: ***www.independentage.org/information/housing-options/home-adaptations***

For grants, visit ***Disabled Facilities Grant****:* ***www.dlf.org.uk/content/full-list-factsheets*** *and* ***Independence at Home****:* ***www.independenceathome.org.uk***

Find your local council: ***www.gov.uk/apply-home-equipment-for-disabled***

For most people in the UK, lockdown has forced changes to many aspects of life. Ataxia UK asked the ataxia community how lockdown has affected them.

DEREK WOOD (right)

"I'm coping rather well with the lockdown, although my day-to-day life has changed quite dramatically. I try to be as active as possible, both physically and mentally. Where I used to attend a weekly, seated Pilates class, this has been replaced by an online class with the same teacher. For mental stimulation I attend two different Spanish classes, both of them now via Zoom. I am a regular on the Ataxia UK **InControl** Zoom sessions and very much enjoy the interaction with all the other participants, plus the variety of topics we discuss. Overall my attitude always was 'keep busy' and this has not changed, only how and where it all happens. I have always been a 'glass half full' person and I have managed to maintain that."

MARI AKHURST (right)

"Being an athlete, my life before lockdown was extremely busy. I've had spare time and it's been nice to relax. I've hosted Q&As that have allowed me to relive some wonderful experiences and fantastic memories. I have also decided to become a volunteer for Ataxia UK to give back and to say thank you. I am in the process of trying to get a powered chair and have a standing frame on the way, which will all help to make me more independent. Try to do something that puts a smile on your face every day; that may just be completing a simple task. Every Monday I try and find one positive from the week before."

JUDY

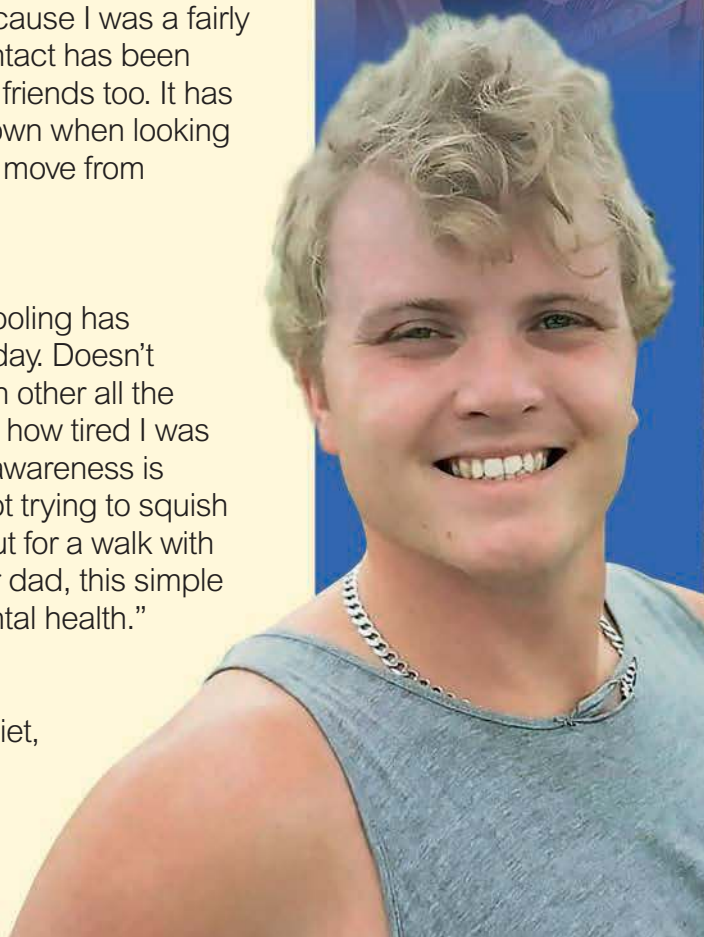
"In many ways, lockdown has not been too bad for me because I was a fairly solitary person anyway, so all the Zoom and FaceTime contact has been good! I have enjoyed more 'contact' from my children and friends too. It has been easy to mix age (I'm 71), ataxia and Covid-19 lockdown when looking for symptoms! The lockdown has certainly highlighted the move from independence to dependence for me."

MARYHR VIA HEALTHUNLOCKED

"I love having my husband working from home; home schooling has turned out a blessing and we all eat lunch together every day. Doesn't mean I don't also tear my hair out with us all on top of each other all the time! But... reduced social engagements have highlighted how tired I was getting with things others take in their stride, and this self-awareness is valuable. I don't neglect my daily stretches because I'm not trying to squish everything into the evenings after a manic day. I can get out for a walk with my poles every day because I can leave the kids with their dad, this simple thing has made a huge difference to my physical and mental health."

SAM PARDOE (right)

"I am focusing on my mind and nature. Dieting on a keto diet, losing pounds, and building a YouTube channel. Playing dodgems with people when I go shopping once a week."



LIT SMITH

"My visitors have stopped coming. My great husband does all my caring - so lucky to have him. His life has changed a lot - always at home with me. Works from home with many Skype calls, no golf or rugby. Organises all my shopping, cooking and washing."

TALLULAH CLARK (right)

"I've been doing physio and mat exercises in the kitchen. Someone kindly gave us a stationary bike, which was amazing as I can't go out for bike rides. I've been cooking a lot, which I find therapeutic and it's a nice feeling preparing a meal for the family as they are normally doing things for me. I've also been blogging and received a First in my dissertation!"

FEBRUARY VIA HEALTHUNLOCKED

"My husband goes to the grocery store and does other errands, same as before. The only difference is he sports a mask now! I occasionally go for a drive with him to pick up a takeaway, that's my entertainment these days! I was going to physical therapy appointments weekly, but now just trying to keep doing various exercises for strength and balance at home these days."

DEREK TAYLOR

"I'm a **Friend** of Ataxia UK and **Chair** of the **West of Scotland Branch**. Our Branch has regular Zoom calls and everyone is coping well. I get exercise from walks or YouTube instead of the gym. Although the lockdown has been inconvenient, it hasn't affected me much."

KIERAN HANKIN (below)

"Kieran took part in the **Superheroes Challenge** in June, and cycled over 80km at home prior to that for training. Kieran has 'live school' maths and literacy lessons every day and plays a lot of *Fortnite!*"

Ataxia UK's Virtual Conference

The conference will be held ONLINE on Thursday 15, Friday 16 and Saturday 17 October.

Apologies to anyone who saved the first weekend of October, we have moved the date to accommodate some key participants!

The sessions will be online, including **Research Updates**, **Doctors Q&As** and **'It Works for Me'**. We will share the results of our **Wellbeing and Financial Inclusion** surveys and the plans they have provoked, plus the changes to our **Governance** (see p.5). New this year is **'Birds of a Feather'**; an opportunity to meet and exchange tips and information with others affected by the same ataxia as you in a facilitated small group.
There will be a variety of smaller group sessions including **Benefits**, **Covid-19** and the **Sheffield Children's Ataxia Centre**, plus workshops including **Speech Therapy**. We hope **Paul Coia** will host the final day on **Saturday 17 October**.

The Conference is free, with a suggested donation per each session. View the programme and reserve places here:
www.ataxia.org.uk/Event/ataxiaukvirtualconference.

We hope a **16-30's online Conference** will follow before the end of the year.

Relaunch of 'All About Ataxia'

Over the years, we have run '**All About Ataxia'** seminars for people newly diagnosed with ataxia. They are also useful for others who have been diagnosed for a while. They are based around videos made with the clinicians and therapists at the **Sheffield Ataxia Centre** and presented by people who are affected by ataxia.

The seminars offer the opportunity to:

- Understand the medical implications of ataxia and what can help you
- Hear how the facilitators have learned to live with ataxia and remain active
- Learn from other participants how they are facing the diagnosis
- Understand what support and services Ataxia UK offers.

When the risk of Covid-19 has receded, we will offer the opportunity to attend the All About Ataxia seminars in person. Meanwhile, our first online seminar will be held on Zoom on the afternoons of **Tuesday 6** and **Wednesday 7 October**. Bookings will open on the website on **1 September**.

Our thanks to **Robert Perkins**, **Trustee of Ataxia UK**, who has filmed, directed and edited new videos, and to the staff of Sheffield Ataxia Centre who offered their time to be interviewed.

Previous participants have said: "Loads of good information", "Our facilitators were very well informed and helped to make the day a success", "Meeting others with ataxia was inspirational".

Supporting your child at school

An Educational Healthcare Plan (EHCP) is designed to support children and young people who have ataxia throughout school. This article explains how the plan can help and how to get one.

An ataxia diagnosis is difficult for anyone at any age, but receiving one during childhood can present challenges at school. There are different forms of extra help that should support children with a disability throughout their school years. There are usually two levels of support for children with **Special Educational Needs (SEN)**; SEN support that mainstream state schools must always provide, and EHCPs that are available when SEN support is not enough. EHCPs cover educational and health and social needs, and provide the additional support to meet those needs.

If you think an EHCP would benefit your child, you can request for an EHCP assessment (anyone over the age of 16 can request an assessment themselves, or by anyone else who thinks an assessment is necessary e.g. doctor, teacher, family friends etc.) by contacting your local authority. GOV.UK has a 'finder' if you are unsure who your local authority is: **www.gov.uk/children-with-special-educational-needs/extra-SEN-help**

When you request an assessment, they may ask for school reports, doctors' assessments and a letter about your child's needs. Your local authority will inform you of the decision within 16 weeks.

If successful, your local authority will create a draft plan and send you a copy. However, it is not uncommon to be rejected and the process can be a challenge. We have heard from Friends that it can be tough, but also that it is worth trying.

Remember that you have the right to challenge your local authority if they decide to not carry out an assessment or if they reject the assessment and do not create an EHCP. If you cannot resolve a problem with your local authority, you can appeal to the **Special Educational Needs and Disability (SEND) Tribunal**.

Sometimes, local authorities have organisations that help parents understand the process and support with written work. You can ask your local authority for information on this.

To get a better understanding of whether your child needs this level of support, you can book an appointment to speak to their ***school's head teacher*** *and the* ***Special Educational Needs Co-ordinator (SENCO)****. Find out more information via* ***Scope*** *here:* ***https://bit.ly/2UZvjOR*** *or* ***GOV.UK: www.gov.uk/children-with-special-educational-needs/extra-SEN-help***

Harriet's take on our virtual activities

Every Friday since April, we have hosted a virtual activity for the ataxia community. From bingo to music, exercise classes to discussion groups, we have had over 240 people take part.

We interviewed **Harriet Bonney**, former **Chair of Ataxia UK**, who has attended the majority of our activity sessions. Harriet was diagnosed with idiopathic cerebellar ataxia around 30 years ago and here she shares her thoughts of the activity programme with our **InControl Manager**, **James Atkins**.

What caught your interest in coming along to the activity sessions?

As I am on the **Steering Group** for the **InControl project**, my initial motivation was to be supportive of the **InControl Team**. However, I also wanted to be supportive of the initiative, which I thought was an excellent one, particularly in the current climate where face-to-face interaction has been extremely limited.

What were your initial thoughts on how the sessions would run? Did you have any reservations?

I didn't really have any initial thoughts. I went into the sessions with a totally open mind, which I think is the best way with new experiences. In relation to reservations, the first session was on the TV series **'Noughts and Crosses'**. I had started but not finished watching the series, and I was concerned there might be spoilers. I also had concerns that, because I hadn't watched the series in its entirety, I wouldn't be able to participate in the discussion - I needn't have worried. We watched clips on YouTube throughout the session (which are sent beforehand) and the discussion is always based around those. I would like to stress you don't need to have read the book or watched the film or TV series that the discussion is based on before you attend.

How did you find using Zoom?

I hadn't heard of Zoom before Covid-19. I had used it a couple of times

before the first activity session and I thought it was excellent - very user-friendly. I have hearing problems but think the clarity of it is excellent. I think it works very well for the sessions.

What have you found to be the most beneficial from participating in the virtual activity sessions?

I am a member of a couple of book groups and really enjoy hearing different opinions and interpretations of the same text. With the activity sessions, I really enjoy the different themes every week, having a different activity to focus on each week, culminating in a discussion and listening to the opinions of others. There is, of course, an important social aspect to it too. Nothing obviously beats face-to-face interaction but this is, absolutely, the next best thing. The other important thing for me is this has nothing to do with ataxia and is a welcome and complete distraction from it.

Which session did you enjoy most and why?

I think the discussion on the TV series **Normal People** based on the book by **Sally Rooney**. I thoroughly enjoyed the TV series anyway and would've watched it regardless, but I just found the discussion something else. The TV series deals with some very sensitive and intimate issues, and the honesty and candid approach of the people taking part in the discussion, as well as listening to and respecting different opinions, was excellent.

What would you say to people who might be interested in coming along to a session?

I would say absolutely try it. Don't be afraid of the technology. It is easy to use. You don't have to participate in the discussions, you can just watch and listen. As I said, you don't have to have read the book, watched the film etc. I find the discussions very enjoyable. They encourage me to watch and read things outside my comfort zone and think about things I wouldn't necessarily think about.

Anything else you would like to add?

If you are dealing with speech problems or general difficulties in relation to your ataxia, please don't let that stop you from joining. If there is something you find too hard in the sessions, let us know because they need to be as inclusive as possible for everyone.

The community contribute topic ideas, if you have one, please email the InControl team at ***volunteering@ataxia.org.uk****.*

We would love to hear from you!

hank you to everyone who has given a donation in memory of a loved one

Leaving a legacy
is one of the most enduring ways
to make an impact

Much of our research
has been made possible
by the foresight and generosity
of our Friends and supporters
who have remembered our work
when making their will

We currently have more than
20 research projects underway,
all of which are funded,
at least in part,
by gifts left to us

Your legacy can be hope for the future